DOCUMENT RESUME

ED 414 664 EC 306 009

AUTHOR Parette, Howard P., Jr.
TITLE Interactive CD-ROM Technology for Family-Centered Augmentative and Alternative Communication Decision-Making across Cultures.
INSTITUTION Southeast Missouri State Univ., Cape Girardeau.
SPONS AGENCY Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE 1997-11-21
NOTE 9p.; Paper presented at The Council for Exceptional Children's Division for Early Childhood, International Early Childhood Conference on Children with Special Needs, (New Orleans, LA, November 21, 1997).
CONTRACT H029K50072
PUB TYPE Reports - Descriptive (141) -- Speeches/Meeting Papers (150)
EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Augmentative and Alternative Communication; *Communication Aids (for Disabled); Cultural Influences; Decision Making; *Disabilities; Elementary Secondary Education; Family Involvement; *Hypermedia; Language Minorities; Minority Group Children; *Multilingual Materials; Optical Data Disks; *Selection Tools

ABSTRACT

This paper highlights features of an interactive, bilingual CD-ROM currently under development that is designed to be used for augmentative and alternative communication (AAC) decision making with professionals and families of children with disabilities. The CD-ROM is scheduled for release in the spring of 1998 and will: (1) provide information and multimedia vignettes designed to sensitize related service personnel to child, AAC device, family/social, cultural, and system issues to consider regarding the selection and use of AAC devices; (2) provide structured procedures and checklists to use during the planning, implementation, and evaluation of the AAC devices; and (3) provide simulated practice in the use of procedures. These interactions are meant to assist personnel in schools and in state, federal, and private agencies and organizations to serve children with disabilities and their families appropriately. The paper discusses the data collection efforts prior to the development of the CD-ROM, the information and services that families of children with disabilities need, respecting family values and culture, and helping families use AAC devices. The features of the CD-ROM are explained and pictures of sample screens are provided. Appendix A provides a summary abstract of the background, data collection, and data analysis of the Department of Education Special Project on which the paper is based. (CR)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 414 664

Interactive CD-ROM Technology for Family-Centered Augmentative and Alternative Communication Decision-Making Across Cultures

Presentation made at the The Council for Exceptional Children's Division for Early Childhood,
International Early Childhood Conference on Children with Special Needs

New Orleans, LA
November 21, 1997

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Presenter:

Howard P. Parette, Jr., Ed.D.
Department of Elementary, Early, and Special Education
Southeast Missouri State University
One University Plaza
Cape Girardeau, MO 63701-4799
(573) 651-5048 (Office)
(573) 651-2410 (FAX)
email: pparette@semovm.semo.edu
website: http://economics.semo.edu/parette/homepage

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL HAS BEEN GRANTED BY
PARETTE
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

This presentation is supported by Grant No. H029K50072 from the U. S. Department of Education to the presenter. Opinions expressed herein are those of the authors alone and should not be interpreted to have agency endorsement.

EC 306 007

BEST COPY AVAILABLE

Interactive CD-ROM Technology for Family-Centered Augmentative and Alternative Communication Decision-Making Across Cultures

This presentation will highlight features of an interactive, bilingual CD-ROM currently under development that is designed to be used for AAC decision-making with families and professionals. The CD will be available Spring, 1998, for national dissemination. A copy of the abstract for this U.S. Department of Education Special Project is attached in Appendix A. An overview of findings will be presented followed by a description of features of the CD.

Developing the Knowledge Base

Prior to development of the CD-ROM, an extensive knowledge base was developed using (a) literature reviews, (b) Expert Panel, (c) Family Advisory Board, and (d) focus group and structured interview findings.

Background

The focus groups and individual interviews for this project were arranged and conducted by Moderators at each of five national sites (Arkansas, California, Illinois, Missouri, New Mexico). The Moderators were provided training regarding cultural sensitivity to enable them to be responsive to the unique cultural needs of each participant. Moderators were asked to: (a) conduct and videotape 1-2 hour for additional data and CD-ROM production, (b) ask participants to complete questionnaires, and (c) secure consent forms.

Preparing for data collection. Each Moderator prepared in different ways to conduct the focus groups and interviews. In some cases the researchers worked through community liaisons or advocates to develop trust and rapport to gain entrance into a targeted community. In some cases interpreters were used. Moderators were sensitive to such cultural symbols as colors worn; in a large inner city colors could not be worn that were used by gang members, while on a Navaho reservation, colors also had special meaning. Interviews were arranged at times and locations convenient for family members. Researchers were respectful of the time, space and reciprocity issues for each cultural group who participated. All families received a small stipend or gift certificate for food.

Changes in data collection process. Researchers balanced the need to maintain adequate research stability and integrity of protocol and procedures with respect for difference in family culture and comfort levels. It was a balance between gaining the family "voice" with the research agenda. Not all families were comfortable with focus groups, so individual interviews were conducted. In European American interviews, for example, family members were more comfortable with demographic and AAC questionnaires. In other families, they were fearful of "government" and were less comfortable with giving demographic information or completing questionnaires. On a Navaho reservation, for example, one researcher spent several hours developing rapport and trust and was honored to be invited into a home for an interview. In this situation, videotaping and extensive questionnaires were not appropriate. In some situations, researchers felt that questionnaires inhibited the participant's willingness to speak; in these situations they reduced the amount of paperwork and began the interviews with giving families an opportunity to "tell their stories." Interviews and focus groups ranged from 1-2 hours in length.

Data Analysis

Data analysis was continuous so that an emergent design could respond analytically to what was heard from subsequent interviews. Interviews were transcribed and content analyzed simultaneously as the issues and themes emerged from the family voices. Issues of credibility of data were addressed to enhance rigor of design. Credibility addresses the issues of integrity and congruence between con-

structed realities of the families and those realities represented by the research team and attributed to the families. The following three techniques were used.

Triangulation of data. This involved bringing more than one source of data and more than one researcher's perspective to bear on understanding the issues and perspective of families. Focus group and individual interviews, questionnaire data, multiple researchers, expert panel, consumer advisory group, and video tapes were used to corroborate data. The perspectives of eight researchers/moderators and assistant researchers were involved in conducting interviews and analyzing data. The questionnaire data supported the interview findings.

Group debriefings. During ongoing discussions and telephone conference calls, researchers discussed collective ideas and perceptions of data and emerging themes and issues. Working with several researchers, many in different time zones, created difficulties in regular communications, however the use of e-mail and meetings as several national conferences aided the ability of researchers to debrief. Interviews on the videotapes helped the researchers to see and know the families, thus enhancing data review and interpretation.

Member checks. This is a recurring process of presenting information and interpretations to family members for discussion in a process that draws the families into checking the credibility of research and ultimately it's application. The consumer advisory group gave feedback and reflection on the findings of the study (e.g. does this summary reflect what you think was said? Do you have any additional comments?). Member checks resulted in clarifying several concepts into more family-centered perspectives.

Following established qualitative analysis procedures, we began by reading and rereading the transcripts to identify major themes or issues for families. Five levels of analysis were then performed:

1. A first researcher read transcripts. Major themes and issues in "synthesis statements" in the margins of transcripts (see below).
2. A second and third researcher read the transcripts and validated the original "synthesis statements." These researchers could also add issues or identify additional themes. If there were any points of disagreement, they were discussed until consensus was reached.
3. The "synthesis statements" were used to identify the major themes and issues for understanding AAC decision making from a cultural perspective. Some of the initial issues that emerged were broad, for example: time issues, professional responsibilities, extended family involvement, support groups, transportation, and training issues.
4. In an ongoing process, interviews were conducted, reread, and compared to the initial themes and issues observed so that continuous feedback could divide, merge, or create new themes in a "constant comparative method". Issues were organized and integrated into three major themes that emerged.
5. Last, after reaching a point of saturation (no new themes or issues emerging), the themes and issues of AAC decision making were presented to the consumer advisory group for feedback.

Results of Themes

The results are presented in three themes that were identified in the analysis of data. The three themes address the broader question of the study "What do families of different cultures want professionals to know about AAC decision-making?" More specifically the themes answer three related questions: (a) *How do families want professionals to build family-professional partnerships?* (b) *How do families want professionals to demonstrate respect for family values and culture?* and (c) *What can professionals do to help families learn how to use AAC devices?*

Building Family and Professional Partnerships

Family and professional partnerships can enable families from different cultures and professionals to work together in pursuit of shared goals. Partnerships must be built on trust, and recognize the strengths and capabilities of each member of the partnership. Two major issues emerged for families regarding how they want professionals to build family and professional partnerships: communication and team decision-making.

Culture can influence the content and process of communication, but the communication issues raised in this study were less culture specific and more focused on the general need for clear, accurate, trustworthy, and straightforward communication. Families spoke of the need for professionals to minimize jargon and be honest in their communication. If professionals are uncomfortable about using an AAC device or must learn how to use the device themselves, they should communicate this to family members. Family members also wanted clear communication regarding such issues as ownership of AAC devices, repair periods, and waiting periods for initial receipt of devices.

Families face a multitude of decisions when they have a child with disabilities. In team decision making, families wanted to be key in providing information during the assessment process. Families wanted professionals to recognize that their child may refuse to participate in evaluations by new team members. They wanted professionals to establish rapport with their child prior to assessment and adapt procedures where necessary. Families indicated the importance of their role in evaluations and wanted professional to recognize their recommendations were based on short-term contact with the child, versus the lifetime contact of the family. Families discussed the importance of considering the opinions of the elder members and extended members of the family, of inviting them to the assessment.

Families indicated they wanted information regarding the timelines of the AAC device assessment process and they hoped professionals were clear that insurance companies base decision on evaluation information provided by teams. Families did not want the AAC device to be taken away after the child had hands-on experiences and showed a preference and ability to use a device. They wanted the team to ensure that their child would have continued access to the AAC device from time of rental to actual delivery to the family. Families indicated they wanted professional recommendations to be based on objective, not subjective experiences and they did not want the AAC device to be selected for use by many children in lieu of individualizing selection of a device to meet the needs of one child and family.

Respecting Family Values and Culture

Respecting family values and culture is key to becoming family-centered and culturally competent. How do families want professionals to demonstrate respect for family values and culture? Child specific issues and family systems issues emerged in this theme.

Child specific issues. Families wanted professionals to show sensitivity to the child specific issues of culture and disability. They wanted professionals to show sensitivity to terminology when discussing their children and to see their child as a unique individual and not discuss their child collectively as in a group. They wanted professionals to show greater sensitivity to the symbols used in communication devices, avoiding stereotyping of color and symbols. For example, the color black may be used to denote "wrong" or "bad." Family members from the Navaho wanted symbols and colors that were appropriate to their clan. The most important sensitivity issue discussed by family members was the issue of stigma. Families wanted professionals to be sensitive to the "double stigma" sometimes associated with being a member of a minority culture and having a disability. Parents spoke of not wanting to draw "even greater negative attention" to their child. One mother shared, "How is the world going to perceive my child being an African American and also handicapped. That's like two negatives when you deal with a big society that doesn't look very positively upon African Americans."

This issue of stigma was closely tied to the need to have their children accepted into the community and accepted into peer groups.

Family system issues. The collectivist culture of many minority families means that AAC deci-

sion making must consider and support the needs of extended family and siblings. Many parents spoke of how siblings were affected in both positive and negative ways that changed family interactions. Families also wanted professionals to be sensitive to the demands, needs, routines and realities of family life. Issues such as transportation of the device, space for the device, maintenance of the device were all important concerns for families. One parent said she had to purchase a bookcase to put all the materials, manuals and batteries into for safe keeping. Several parents also described the issue of transportation.

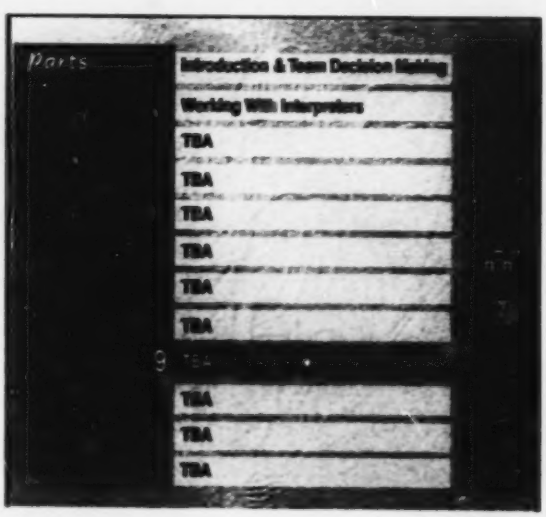
Helping Families to Use AAC Devices

Another theme that emerged from the interviews was the great need that families had for information and training on how to use the AAC device with their child and within their family. Families wanted more information regarding specific information on AAC devices including the range of devices available, critical features of devices, support from vendors, funding process, and warranties. Some families wanted the support information and training materials to be in Spanish or their native language. Other families discussed the need to be connected with other families or parent support groups to gain information and support. Parents needed information on the varying levels of support and information from vendors, and what to expect from vendors.

Families also wanted training on how to use specific AAC devices. They wanted this training for themselves and other extended family members. They wanted to watch other children using similar devices prior to purchase. They wanted to be provided hands on experiences for themselves and other children and family members. They wanted this support prior to purchase and then again after purchase. They wanted professionals to show sensitivity to the family's need for repeated training sessions in order to learn to use the AAC device effectively. They also wanted professionals to show sensitivity to the inordinate amount of time families must wait to receive toll-free technical assistance callbacks from vendors.

Current CD-ROM Features

The following is a brief overview of the current design of the CD that will be discussed in this presentation: Introduction and Team Decision-Making, and Working with Interpreters. Another eight chapters are currently under development, and include the following topics: Working with Teams, Building Family and Professional Partnerships, Respecting Family Values and Cultures, Helping Families to Use AAC Devices, Getting Funding for AAC Devices, and several Day In the Life chapters (which follow different families from various cultures through the entire AAC process). Each chapter will contain all working features such as interactive links, glossary, and games that will be common throughout the program. The chapters will be fully operational on both Macintosh and Windows multimedia compatible computers. The program will incorporate easy access features, such as audio narration, synched textual narration, and multiple interface capabilities to permit persons with a wide range of disabilities to use the program. Personnel are currently digitally recording and editing the narration, digitally capturing and editing video segments and images used in the modules. Each chapter will contain at least 5-10 minutes of digital video. Simple mouse and keyboard controls will be developed to manipulate (like a VCR) the digital movies and synched text. Hot text or links from the narration to additional or more detailed information will be developed.

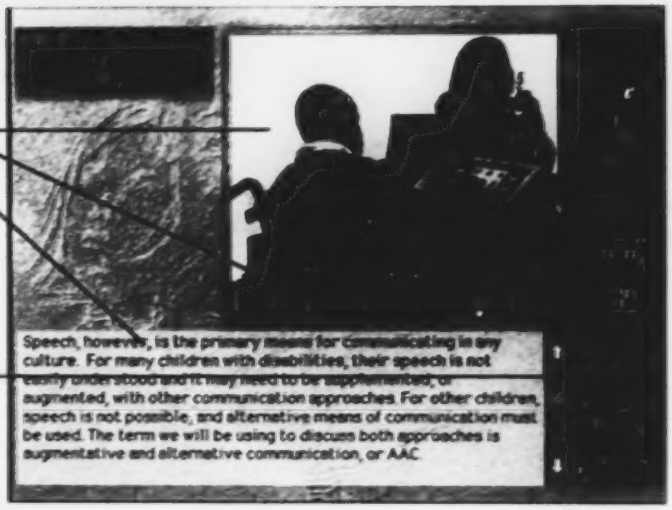


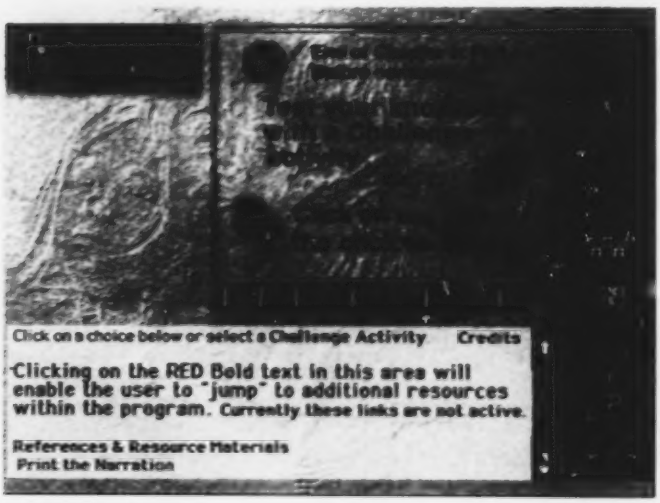
BEST COPY AVAILABLE

Videotape footage, cartoon drawings, animations, and special effects will be presented in a view window that may be controlled by the user.

Screen presentations will feature audio narration synched with text.
(Note: The final version will be available in both English and Spanish.)

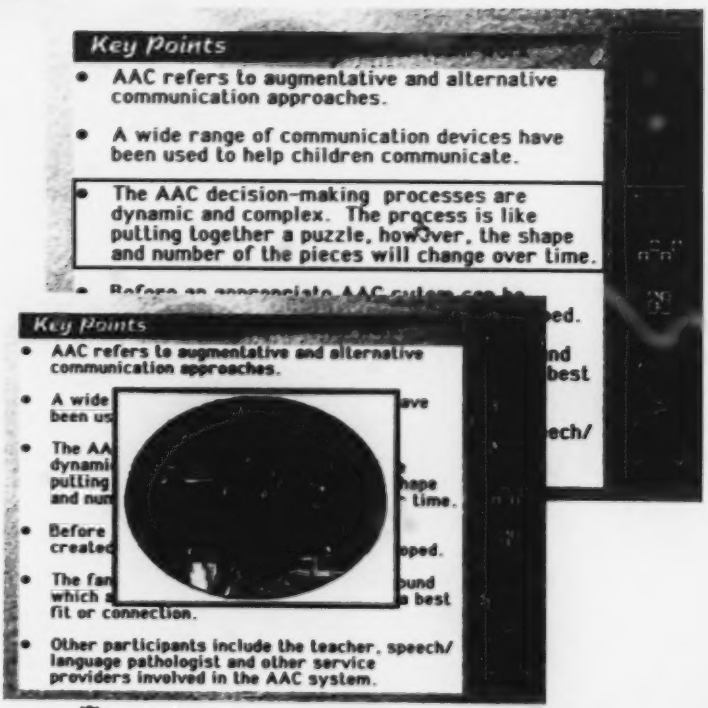
Navigation buttons are conveniently located to the right of each screen.


Speech, however, is the primary means for communicating in any culture. For many children with disabilities, their speech is not
augmented, with other communication approaches. For other children,
speech is not possible, and alternative means of communication must
be used. The term we will be using to discuss both approaches is
augmentative and alternative communication, or AAC.

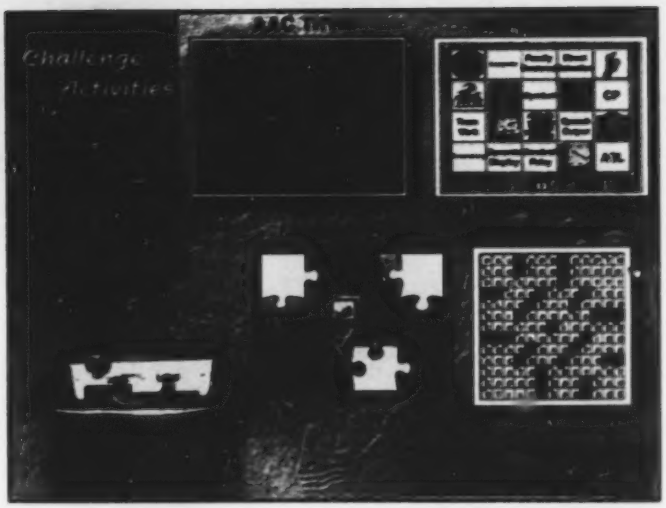

Click on a choice below or select a Challenge Activity
Credits
Clicking on the RED Bold text in this area will enable the user to "jump" to additional resources within the program. Currently these links are not active.
References & Resource Materials
Print the Narration

Users may test their knowledge with Challenge Activities at the conclusion of a module, or obtain additional information (e.g., references and resource materials, print narration, etc.)

Key points synched with narration may be reviewed at the conclusion of each chapter. Each key point is linked to previous narration and images presented which is replayed on mouse click by user.

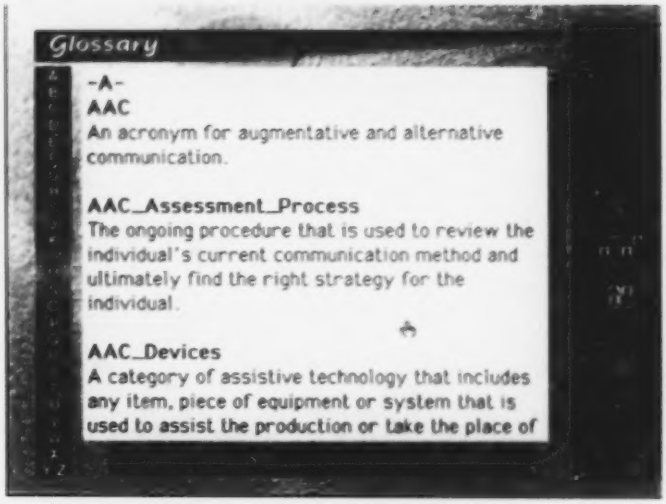

Key Points
AAC refers to augmentative and alternative communication approaches.
A wide range of communication devices have been used to help children communicate.
The AAC decision-making processes are dynamic and complex. The process is like putting together a puzzle, however, the shape and number of the pieces will change over time.
Key Points
AAC refers to augmentative and alternative communication approaches.
Other participants include the teacher, speech/language pathologist and other service providers involved in the AAC system.

BEST COPY AVAILABLE



Challenge activities present the user with a variety of opportunities to review content in game formats.

Users may obtain definitions regarding terms used in the narration. Other terminology that might be used by professionals and vendors during AAC decision-making is also included.


Glossary
-A-
AAC
An acronym for augmentative and alternative communication.
AAC_Assessment_Process
The ongoing procedure that is used to review the individual's current communication method and ultimately find the right strategy for the individual.
AAC_Devices
A category of assistive technology that includes any item, piece of equipment or system that is used to assist the production or take the place of

Additional information regarding the availability of this CD may be obtained by contacting:

Howard P. Parette, Jr., Ed.D.
Department of Elementary, Early, and Special Education
Southeast Missouri State University
One University Plaza
Cape Girardeau, MO 63701-4799
(573) 651-5048 (Office)
(573) 651-2410 (FAX)
email: pparette@semovm.semo.edu
website: http://economics.semo.edu/parette/homepage

BEST COPY AVAILABLE

Appendix A

ABSTRACT

Culture, Families, and Augmentative and Alternative Communication (AAC) Impact: A Multimedia Instructional Program for Related Services Personnel and Family Members, U.S. D. E. Contract No. H029K50072

This project was one of 22 Special Projects funded in 1995 and is designed to develop decision-making strategies and materials related to the prescription of AAC devices for young children with disabilities. It is also designed to train related services personnel and family members nationally in their use. Little attention has been given by related services personnel (e.g., speech/language pathologists, occupational therapists, physical therapists, technology specialists) and vendors to the impact of AAC devices on family functioning and cultural diversity prior or subsequent to the introduction of devices (e.g., demands placed on families to attend training sessions, stress and changes in routines which may result, cultural values and their relationship to AAC prescription). This can result in the provision of inappropriate AAC devices. The Project will result in the development of the **first interactive bi-lingual CD-ROM** designed to be used by related services personnel at the pre- or in-service level, vendors, and family members from diverse cultures to develop competencies that assist in effective AAC decision-making. The instructional materials will: provide information and multimedia vignettes designed to sensitize related services personnel to child, AAC device, family/social, cultural, and system issues to consider regarding the selection and use of AAC devices; provide structured procedures and checklists to use during the planning, implementation, and evaluation of AAC devices; and provide simulated practice in the use of the procedures. These interactive materials will assist personnel in schools, state, federal, and private agencies and organizations to appropriately serve children with disabilities and their families. They will also enable service providers to make the most appropriate decisions about the prescription of AAC devices while balancing child, AAC device, family, cultural, and system resource considerations.

The project objectives will be achieved through activities during three phases: (a) ***Phase 1*** will involve identification of critical AAC family and cultural impact issues through Focus Groups conducted in five states using families from various cultures, vendors of AAC devices, and related services personnel; (b) ***Phase 2*** will involve development of a draft version of the interactive AAC training materials, creation of initial versions of the materials, alpha testing in urban and rural field sites, and creation of a CD-ROM that will be beta tested using targeted field sites nationally; and (c) ***Phase 3*** will involve mass production and widescale dissemination of the training materials along with multifaceted training activities nationally. As many as 130,000 individuals may be trained in Year 3 and in subsequent years using the interactive materials.